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ABSTRACT

The paper discusses the rehabilitation of pediatric cancer patients undertaken by a multidisciplinary team with the aim of returning the children to the classroom. Details including transportation, tutoring, and preparation of classmates are considered. (CL)

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RETURNING THE CHILD WITH CANCER TO THE CLASSROOM

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Abstract:

The Cancer Center, Inc. of Northeast Ohio, with headquarters in Cleveland, has developed a multi-disciplinary team approach to the rehabilitation of cancer patients in the home setting. This demonstration project is funded by the National Cancer Institute* for a three-year period and consists of a Project Director, three Social Workers, two Public Health Nurses, a Physical Therapist, Occupational Therapist, Vocational/Educational Counselor, Health Educator and Child Life Worker.

This paper discusses the rehabilitation of pediatric cancer patients and their return to the classroom; however, the concepts can be applied to any child with a chronic illness or a handicapping condition.

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RETURNING THE CHILD WITH CANCER TO THE CLASSROOM

Paulette Tharp*

Returning to school is an important aspect of the rehabilitation of a child with cancer. Children often find support and hope among their friends at school and are anxious to be with them. School is a fundamental part of a child's life and is a link with normal living - the way things were before. Life will never be exactly the same for the child or his family, but varying levels of adjustment can be reached and once the adjustments have been made and a program of rehabilitation begun, a good quality of life can be achieved.

It is not easy, however, for a child with cancer to return to the classroom after a prolonged absence. Preparation and planning is vital to ease re-entry. Questions will be asked by classmates, teachers, and other parents about the physical and emotional changes that have occurred. The child must be helped to adjust to the new situation. Children have varying degrees of capability in handling the problems that arise.

The National Cancer Institute Division of Cancer Control and Rehabilitation is funding a three year At-Home Rehabilitation Team Demonstration Project at the Cancer Center, Inc. of Northeast Ohio (with headquarters in Cleveland) until Feburary 1979. This multi-disciplinary team is made up of a Project Director, three Social Workers, two Public Health Nurses, a Physical Therapist, Occupational Therapist, Vocational/Educational Counselor, Health Educator, a Child Life Worker, and a Consulting Psychiatrist.

As the Child Life Worker I have had considerable experience in the last two and one-half years in planning and preparing for the return of a child with cancer to school. The rehabilitation program begins while the child is still in the hospital when the Team Social Worker is introduced by the attending physician,

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hospital social worker, or oncology nurse to the child and family prior to discharge. The Social Worker, who acts as the Team's coordinator, follows up with a home visit to determine if the family needs special equipment and/or services to facilitate the child's rehabilitation. Continuation of the child's education is a major concern in that assessment.

The assessment is presented by the Social Worker at the weekly care conference. The entire Team discusses the case. Since there are children involved as patients and siblings, the Child Life Worker will accompany the Social Worker on the home visit.

The Social Worker and the Child Life Worker make frequent home visits together to help the patient and family make as satisfactory an adjustment as possible. The Child Life Worker uses specially designed play equipment geared to the child's individual ability in an effort to aid in his adjustment and understanding of the illness. The child's fears about returning to school and worries about peer approval and acceptance of physical changes such as hair loss, weight loss, mouth sores, or the loss of a limb must be overcome. But once the physician and the Team have determined that the child is ready to resume his studies in a classroom environment, everything is done to make the transition as easy as possible.

If the child is of school age, the Team Vocational/Educational Counselor is asked to participate in the school planning. She is the planner and organizer of the child's return to school. In conjunction with the Physical Therapist, the Vocational/Educational Counselor reviews the architectural barriers the child will have to cope with at school. Seating arrangements, stairs, hallways, accessibility of facilities such as washrooms, lunchrooms, and playgrounds are inspected. Jennifer, a 6-year old with an above-the-knee amputation was returning to an old multi-level school building on crutches.

Team Planning arranged for her to arrive early to school and to leave a little earlier in the afternoon so as to avoid the rush of the other students in the hallways. Her teacher assigned a "helper" to get her lunch since access to the cafeteria was up and down several flights of stairs. When Jennifer obtained her prosthesis and became skilled in its management through gait training with the Team Physical Therapist, she was able to negotiate the stairs by herself. A classroom presentation was given to three first grades to explain what had happened to Jennifer over the summer. Follow-up letters were sent home to the parents of all three classes in case there were any questions. What was important was that Jennifer was able to return to school prior to being fitted for her prosthetic device because of the suggestions of the Team and the cooperation of the school personnel, and her schooling resumed earlier than it might have.

Transportation to school, if needed, can be obtained by the Team. Arrangements were made for one 9-year old with Ewings Sarcoma (a bone cancer) to ride a special bus provided by the school. In time she was able to ride one way and to walk the other. She is now able to ride a bicycle to school which she prefers to do, but she knows that school transportation is available when she needs it.

Prior to returning to school or even perhaps while attending school the child may require tutoring. Schools, with the aid of the Vocational/Educational counselor or the parent, can make special arrangements for tutoring help. Sometimes a child is not feeling well after chemotherapy or radiation treatments and cannot attend school on a regular basis. Home tutoring helps the child to keep up with school work in such cases. One school, for example, allows a high school junior to audit her classes. She attends school when she can but maintains her studies at home and the evaluation of her progress is made by the tutor in conjunction with school officials.

There is another important aspect of returning a child with cancer to school and that is the teacher's and classmates' preparation for his return. The At-Home Rehabilitation Team has been able to facilitate many school returns by special classroom presentations attended by school personnel, students, patient, and the parents. These presentations are prepared by the Team's Health Educator with the use of audio/visual educational techniques. Normal and abnormal cell growth is explained; treatment procedures are graphically portrayed; and hospital facilities and hospital personnel, even the patient, are pictured. Appropriate Team members work together to present these programs in consultation with school personnel, the family, and the child himself. The programs are tailored to the grade level and the concerns of all involved. For example, a "mini-team" consisting of the Vocational/Educational Counselor, Health Educator, Physical Therapist, and Child Life Worker designed and implemented a school program around the questions the students were asking their teacher about Willie, aged eight. Willie's cancer was an osteogenic sarcoma, a bone cancer, which resulted in a hip disarticulation, an amputation of the entire leg. Some of the questions asked by his classmates were: "When you remove part of the body, does the rest of it stop working?" "Did Willie's cancer start from the fall he had on a piece of glass and cut his leg badly?" One child asked: "If I cut myself will it also mean to have an amputation?" The children wanted to see Willie and wanted to know what they could talk about besides his leg.

The Team's program was prepared for two third-grade classes with Willie's knowledge and consent, although he didn't want to be present at the program. It was scheduled to be given before he returned to the classroom.

Unfortunately, Willie's condition deteriorated rapidly and he did not return to school; however, it was felt by the Team and school personnel that

the program as prepared should be presented. The Vocational/Educational Counselor introduced the program to the 52 children in the two classes. The Health Educator explained the words "cell" and "tumor"; the Physical Therapist talked about the surgery and showed the mechanics and use of a prosthetic limb. The Child Life Worker discussed the range of feelings a child experiences during hospitalization, the impact of the diagnosis of a serious illness, and what the loss of a limb means. All Team members emphasized what positive measures can be taken to help a child with cancer, and what the Team can do to help in rehabilitation. The topics were discussed with the use of slides, models of hospital treatment apparatus such as the container of introvenous fluids, a human skeleton, leg bone replica, and an actual prosthetic leg. Emphasis was placed on the fact that cancer is not contagious and that it is a relatively rare occurrence, and that, although no one was sure of its origin, it doesn't come about because of a cut or a fall.

There were many questions and the children did not hesitate to raise them. One child asked, "Can you die from cancer?" This was answered affirmatively and honestly, at the same time indicating that one can die from many causes but that, in the case of cancer, treatment and medication are availabe which, very often, can result in long-term remission or even complete cure.

In a follow-up contact with the school, the Team learned that the children had responded eagerly to the information provided, and the teachers reported that many of the pupils told them that the topic was discussed at family dinner tables. As Willie's condition worsened, the children offered much support, a few of them visiting him at home on a regular basis.

When the teacher told the class of Willie's death, the children were very sad. They shared their feelings and discussed death briefly. They were encouraged to talk to their parents at home so that the questions regarding

an after-life would be answered according to the family's religious beliefs.

The difference in each program depends on the individual needs of the child or class. An educational program on leukemia was designed specifically for teachers in one child's school. It is important for them to know that many children go into remission soon after diagnosis of leukemia and are able and eager to return to school. This understanding of leukemia helps them to know what to expect of the child in terms of educational achievement, behavior, attendance, etc. Jimmy, age 12, however, could not return to school for a long time after his diagnosis of leukemia, due to medication complications, but the staff at his school were interested in knowing more about cancer for their own benefit and as an aid in answering the other pupil's questions. Jimmy welcomed having the teacher explain to the class why had had lost all his hair, why he was so thin, and why had had been out of school for so long, to spare him from having to answer individual questions over and over.

The Team's presentation to the teachers stressed cancer facts in general and leukemia in particular. Individual packets of materials about cancer were prepared for each teacher and included a bibliography of suggested readings for children and adults, literature about cancer prepared by the American Cancer Society, the U.S. Department of Health, Education and Welfare, and the National Cancer Institute; classroom guidelines for teachers about children with cancer, siblings wtih cancer, and parents with cancer; a resource list of community services, and a sample return to school plan.

Another classroom presentation about leukemia was prepared for a fourth-grade class. Jay, a 9-year old twin boy, was returning to class after several months of absence. Jay's teacher had designed a health unit on cancer and the Team was an additional source of information. A coloring book, designed by the Child LIfe Worker and Health Educator was incorporated into a slide show

which explained leukemia and the many different feelings being experienced by an ill child. Medical equipment used in the hospital was demonstrated by the Team's Nurse. After the presentation, the students were given a copy of the coloring book and a health crossword puzzle. The teacher utilized these materials as a follow-up activity for the class.

Returning the child with cancer to the classroom as soon as possible is encouraged by physicians as it is psychologically beneficial. It is a future-oriented activity implying optimism about the prognosis, but return to school can present health problems. If the child has been exposed to chicken pox, the physician should be immediately informed so that gamma globulin can be given to mitigate its effects. Chicken pox can be very dangerous to a child with cancer since many chemotherapy medications suppress the immune defense system. It is important for the teacher and school nurse to be aware that chicken pox, which causes minimal distress to healthy children, can result in death for a child undergoing chemotherapy treatment. Because chicken pox has an incubation period of from 14 to 21 days, a child thus exposed may have to have his chemotherapy treatments postponed so that he will not expose other children in the hospital. Through the cooperation of the teacher, school work can be sent home or the tutor alerted to keep the child abreast of his studies while absent.

Duane, a 10-year old boy with a below-the-knee amputation, is an excellent example of cooperation with school personnel, physician, and members of the At-Home Rehabilitation Team. Just before surgery and immediately after, the Team Social Worker talked with Duane and his family in the hospital. Once Duane was discharged the family's needs were further assessed during the course of a home visit. The Social Worker assembled the group of Team members to help meet those needs.

The child life worker helped him understand his condition and express feelings he had about his diagnosis and loss of his limb. The physical therapist helped him carry out an exercise program begun in the hospital and continued at home. Arrangements for tutoring were made by the Vocational/ Educational Counselor. The Social Worker obtained a home health aid and also provided an opportunity for the parents to vent their feelings about the many changes taking place. Thus, school work was maintained, exercises performed, a prosthetic limb obtained, gait-training established, feelings about treatment and peer acceptance were expressed, and both parents were able to return to work. Four months after surgery Duane was ready to return to school.

At Duane's request, a special classroom presentation was prepared by the Health Educator on his first day back in school, and he was eager to help answer questions. Pictures had been taken by the Health Educator of Duane throughout his rehabilitation period and were incorporated into the lesson. His school attendance became regular interrupted only by return trips to the hospital for chemotherapy, and Duane was back to his normal activities including skate boarding!

Communication and cooperation among school personnel, patient, family, classmates, and the At-Home Team has been important in facilitating a successful re-entry into the classroom environment. Through the efforts of the Team, school personnel, medical staff, and the parents, the child achieves a feeling of self confidence and security in returning to school.